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A pilot of clinical performance indicators for suspected childhood epilepsies

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ABSTRACT

Purpose: In response to continuing concerns regarding the quality and equality of care for children and young people, the British Paediatric Neurology Association (BPNA) has supported the development of practical and meaningful audit to support quality improvement.
Method: In 2006, the Children's Epilepsy Workstream in Trent (CEWT) coordinated a retrospective multi-service audit of paediatric epilepsy care against NICE and SIGN guidelines. This aimed to both facilitate quality improvements for participating services and act as a pilot for future potential national audits.
Results: The audit was achieved in 4 hospital services using prospective and retrospective ascertainment methods. 12 performance indicators were applied to each cohort. Overall 54% (12/22) of children with epilepsy had input from a paediatrician with "expertise" and 23% (5/22) had input from an epilepsy specialist nurse.
Conclusion: Audit can be developed for epilepsies that delivers standardised quality metrics against national recommendations. As well as supporting local quality improvement initiatives, comparative and aggregate data can be produced to potentially give regional and national perspectives. The results and experience describe the journey towards the 2009–2012 Epilepsy12 UK multicentre epilepsy audit.

1. Introduction

Epilepsies are the commonest disabling chronic neurological disorders of childhood with a prevalence of approximately 1 in 200 children and an incidence of 50–80 per 100 000 per year.[1,2] In the UK, the majority of children are diagnosed and managed in acute and non-acute secondary level paediatric services with some requiring additional paediatric neurology (tertiary) involvement. There has been longstanding concern regarding misdiagnosis and quality of management.[3]

National recommendations for investigation and management of epilepsies were introduced in 2004,[1,2,4] however meaningful audit against these standards has been difficult.[5]

The Children's Epilepsy Workstream in Trent (CEWT) was established to support epilepsy service development in the Mid-Trent region. In 2006, the British Paediatric Neurology Association (BPNA) commissioned CEWT to coordinate a regional audit pilot to assess the quality of epilepsy care and service provision across Trent.

This paper outlines the journey and evolution of methodologies leading ultimately to the ongoing Epilepsy12 UK national audit.

2. Methods

All paediatricians within the Mid-Trent region were invited to participate. Audit coordinators (Epilepsy Nurse Specialist, Senior House Officer or Specialist Registrar) were identified at each participating service. One Specialist Registrar acted as regional co-ordinator and one Paediatric Consultant acted as clinical lead.

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Ascertainment was undertaken to identify children who were

- assessed for the first time by a paediatric service with a paroxysmal episode(s) within a defined ten week time period;
- the episode(s) were considered by referrer or assessor to be of a possible epileptic nature.

Children with a diagnosis of febrile convulsions were excluded.

No single ascertainment method was found to be achievable and therefore ascertainment strategies were tailored to each individual participating service. The closest 10 week period to a time period ending at the end of June 2004, where ascertainment was possible and records were available, was selected.

Service 1 – Windows-based keyword search (''seizure'', ''convulsion'', ''fit'', ''epilep*'') of archived hospital clinic letters during the defined time period and ward admission records.

Service 2 – General Practitioner referrals to outpatient general paediatricians (data from previous local audit[6]) and keyword search of emergency department records.

Service 3 – Keyword search of acute admissions coding and outpatient letters (data from 2 consultants only available)

Service 4 – Windows-based keyword search of archived outpatient letters

The case notes were obtained based on these initial search strategies. First paediatric assessment was defined as either the first outpatient appointment or the first acute paediatric assessment/admission. The time period examined was 12 months following the first paediatric assessment. Clinical information was obtained from handwritten casenotes, typed clinic letters and discharge summaries.

Proformas based on BPNA previous audit tools[7] were completed for each child meeting the inclusion criteria. The diagnosis made by the paediatric service at first presentation and at the latest assessment 12 months after first assessment was determined. Diagnoses were categorised as epileptic, non-epileptic or uncertain. A number of seizures occurring within a 24 h period were interpreted as a single episode or seizure cluster rather than recurrent seizures. Epilepsy was defined as diagnosed where the documentation showed evidence of diagnosing recurrent epileptic episodes. Data was anonymised and entered into a centralised Microsoft Excel spreadsheet. Data validation and measures of inter-observer variability were not undertaken; this was undertaken within the subsequent national Epilepsy12 audit.[8]

Twelve clinical performance indicators derived from NICE and SIGN recommendations were applied.[1,2,4] The performance indicators were designed on the basis of the following criteria:

- standard defined by national guidance
- performance indicator could be calculated using retrospective casenote analysis
- performance indicators could be meaningfully applied to multiple heterogenous cohorts to facilitate comparative analysis
- results could be translated into a pragmatic service quality improvement agenda

The audit was conducted between March and December 2006.

3. Results

Four hospital based services responded and registered the audit. Cohort 4 contained children presenting 17 months after cohort 1–3. NICE recommendations were published during the time period examined for cohort 1–3 and before that for cohort 4.

The initial search methods identified 236 children. Case notes were available for 225 and of these 160 were excluded using stated criteria. Total number included was 65 (Table 1).

The median age at presentation was 6.5 years; 48% were female (Table 2). Learning difficulty was defined as present if referred to in the notes or that the child had a diagnosis of global developmental delay. 56% of children had their first assessment in a paediatric clinic setting and 44% in an acute paediatric setting.

22 children had a diagnosis of epilepsy by 1 year of which 12 were commenced on antiepileptic medication (Fig. 1).

The results for each performance indicator (PI) are summarised in Table 3.

PI1: 54% of children diagnosed with epilepsy had evidence of input by a paediatrician with expertise in epilepsy (Table 4). For this pilot, ''paediatrician with expertise'' was defined as those consultant paediatricians who declared an interest or expertise in epilepsies during a previous Trent scoping survey.

PI2: 23% diagnosed with epileptic seizures in 1st year had evidence of referral to, or involvement of, an epilepsy nurse by 1 year. Any evidence of hospital casenote documented referral or contact during the first year was accepted.

PI3: A first clinical assessment was defined as appropriate if it contained any key features. *46% had of evidence of an appropriate first clinical assessment.

PI4: 100% of children commenced on antiepileptic drugs (AEDs) at any time in the first year had a diagnosis of epileptic seizures at 1 year.

PI5: 81% diagnosed as epileptic seizure(s) in 1st year had seizure classification by 1 year. Any attempt at seizure classification was accepted including 'unclassified'.

PI6: 50% diagnosed as having epileptic seizures (not including single epileptic seizure or seizure cluster) had syndromal or syndromal category classification by 1 year. Any attempt at epilepsy syndrome classification was accepted including 'unclassified'.

Table 1
Summary of the methodology and numbers included for each cohort.

	All	Cohort 1	Cohort 2	Cohort 3	Cohort 4
Date of first assessment	2004–2005	21/4/04-30/6/04	21/4/04-30/6/04	26/4/04-5/7/04	1/9/05-10/11/05
Location of service		District General	District General	Tertiary Hospital	District General
% general paediatricians in audit for area covered	58% (31/53)	71% (5/7)	83% (5/6)	48% (11/23)	59% (10/17)
Ascertainment method		Coding database & keyword	Coding database & keyword	Coding database & GP letters	Keyword
Inclusion criteria	afebrile seizures	afebrile seizures	afebrile seizures	afebrile seizures	afebrile seizures
No. identified	236	37	16	145	38
Notes unavailable	11	0	0	9	2
Excluded on entry criteria	160	19	8	122	11
N	65	18	8	14	25

Table 2
Demographic details for the cohorts ascertained.

	All	Cohort 1	Cohort 2	Cohort 3	Cohort 4
Median age in years (range)	6.5 (0–16.9)	6.7 (0.4–14.5)	8.5 (3–12)	2.9 (0–14.9)	8.1(0.1–16.9)
Female:male (%)	48:52	67:33	38:63	21:79	64:36
Learning difficulty (%)	7%	6%	13%	0%	8%
First assessment outpatient: acute (%)	56:44	89:11	25:75	14:86	96:4

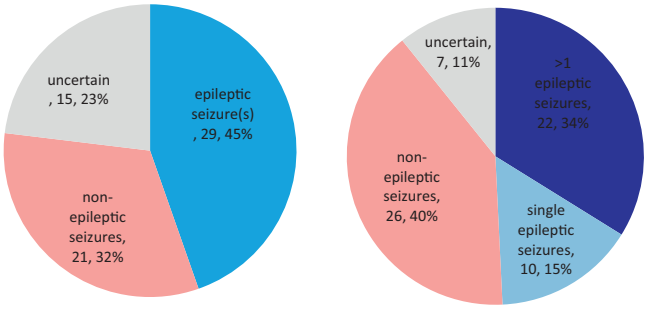

Fig. 1. Pie charts showing diagnoses at first assessment (left) and at 1 year (right).

PI7: 90% children diagnosed as non-epileptic at first assessment did not have EEG at first assessment. Conversely 10% children had EEG where the diagnosis at first assessment was non-epileptic.

PI8: 71% with epileptic seizures at 1 year with an indication for MRI, had MRI by 1 year. Indications used for this audit were age less than two at onset of seizures or diagnosis of a focal epilepsy other than rolandic epilepsy.

PI9: 23% with convulsive episodes of uncertain cause at 1 year or diagnosed as syncope had a 12 lead ECG by 1 year.

PI10: 0% females older than 12 years commenced on AEDs had documented evidence of discussion regarding pregnancy related issues.

PI11: 25% commenced on anti-epileptic drugs (AEDs) had documented evidence of discussion regarding adverse effects.

PI12: 100% diagnosed epileptic seizures meeting NICE referral criteria had evidence of referral to or discussion with tertiary care by 1 year.

Waiting times were determined from the time of referral to the time first appointment offered or acute assessment. 48% of children referred after a non-febrile seizure were seen within the NICE recommendation of 2 weeks.

4. Audit conclusions

Within this pilot no single ascertainment method could be applied consistently. Methods used depended on local systems for tracking admissions and outpatient encounters. The cohort for each centre was defined as being within a 10 week period but again due to the different methods used at each centre the same 10 week period was not used for each cohort. Because outpatient and community paediatric services did not permit any reliable way of identifying patients with epilepsy there was no gold standard to measure ascertainment completeness. Cohort 4 did not include those children initially admitted acutely. Therefore some sampling bias may have been introduced. Due to the time frames used some children began their investigation and management prior to the launch of the NICE guidelines. However the guidelines were applicable at some point in the year of follow up examined for each patient.

The approach relied on retrospective casenote analysis and depended on written documentation as evidence of practice. The validity of diagnoses made was not assessed by this audit.

The audit standards and performance indicators used in this audit relate to processes within NICE and SIGN recommendations. The indicators were designed such that higher quality care could be inferred from a higher percentage score. Targets were not defined and for some indicators, given their definitions and the cohort, a score of 100% may not be appropriate.

Community paediatric services were not able to be included because these services were unable to ascertain the target

Table 3
12 Performance indicators and subset indicators for each cohort and overall.

No.	Performance indicator (PI)	All	Cohort 1	Cohort 2	Cohort 3	Cohort 4
1	Input from paediatrician with expertise	54% (12/22)	43% (3/7)	67% (4/6)	33% (1/3)	67% (4/6)
2	Contact with Epilepsy Nurse Specialist	23% (5/22)	0% (0/7)	0% (0/6)	0% (0/3)	83% (5/6)
3	Appropriate* First Clinical Assessment	46% (30/65)	44% (8/18)	25% (2/8)	50% (7/14)	52% (13/25)
	Age at onset*	97% (63/65)				
	Description of events*	98% (64/65)				
	Duration of events	92% (60/65)				
	Frequency of events*	97% (63/65)				
	Provoking or relieving factors enquiry	73% (48/65)				
	Family History enquiry	82% (53/65)				
	Past Medical History enquiry	94% (61/65)				
	Development/School Performance (if >5yr)*	55% (36/65)				
	General and neurological examination*	98% (64/65)				
4	AEDs only for epilepsy	100% (12/12)	100% (5/5)	100% (2/2)	100% (2/2)	100% (3/3)
5	Epileptic Seizure(s) classified	81% (26/32)	90% (9/10)	83% (5/6)	63% (5/8)	88% (7/8)
	% seizure type used recognised by ILAE	92% (24/26)	100% (9/9)	80% (4/5)	100% (5/5)	86% (6/7)
6	Epilepsy Syndrome classified	50% (11/22)	71% (5/7)	33% (2/6)	0% (0/3)	67% (4/6)
	% syndromes used recognised by ILAE	82% (9/11)	100% (5/5)	50% (2/6)	n/a	75% (3/4)
7	Absence inappropriate EEG	90% (19/21)	100% (4/4)	n/a (0/0)	100% (3/3)	86% (12/14)
8	MRI where appropriate	71% (5/7)	67% (2/3)	100% (1/1)	50% (1/2)	100% (1/1)
9	ECG where appropriate	23% (3/13)	40% (2/5)	0% (0/1)	50% (1/2)	0% (0/5)
10	Discussion pregnancy and AEDs	0% (0/1)	0% (0/1)	n/a (0/0)	n/a (0/0)	n/a (0/0)
11	Discussion adverse effects and AEDs	25% (3/12)	0% (0/5)	50% (1/2)	50% (1/2)	33% (1/3)
12	Neurology referral where appropriate	100% (2/2)	100% (2/2)	n/a (0/0)	n/a (0/0)	n/a (0/0)

* Indicates clinical information needed to define clinical assessment as appropriate.

Table 4
Service Descriptors for each cohort and overall.

	All	Cohort 1	Cohort 2	Cohort 3	Cohort 4
Managed clinical network	Trent Workstream	Trent Workstream	Trent Workstream	Trent Workstream	Trent Workstream
Epilepsy interest group	Regional	Regional	Regional	Regional	Regional
Types of designated clinics available to cohort.		Tertiary Satellite	None	Epilepsy Clinic, Young Persons, Transition,	Seizure Clinic, Transition
Epilepsy patients identifiable by service		Acute/outpatient	Acute	Acute/outpatient	Acute/outpatient
Median waiting time for first outpatient assessment (weeks) (range)	5.9 (0–15.4)	1.2 (0–10.7)	9.0 (8–10)	4.1 (0–15.4)	6.4(4.5–10.1)
Median waiting time for EEG (weeks) (25–75th centile)	5.4 (3.9–8.6)	5.4 (5–6.1)	21.4 (17.4–24.7)	0.3 (0–2.6)	4.3 (2.9–5.9)
Median waiting time for MRI (weeks) (25–75th centile)	0.3 (0–30.6)	0 (0–0.29)	14.1 (14.1–14.1)	0 (0–11.6)	22.9 (22.9–22.9)
Median waiting time for outpatient tertiary opinion (weeks) (25–75th centile)	14.0 (11–16.9)	14.0 (11–16.9)	n/a	n/a	n/a

population retrospectively and 'pull' casenotes to a single location allowing a practical means of reviewing the notes.

The audit conclusions included the following:

- 46% with a diagnosis of epilepsy at one year were not assessed by a paediatrician with defined expertise in epilepsy.
- there was a lack of evidence of appropriate assessment, diagnosis, investigation and communication in 54% of children with seizure(s).
- 23% of children had an ECG where indicated according to NICE recommendations.
- there was a lack of evidence of appropriate input from a children's epilepsy nurse specialist in 77% of children and there were insufficient epilepsy nurse specialists (recommended ratio of 1 epilepsy nurse specialist to 250 children with epilepsy).[9]
- the median waiting times for first outpatient assessment, investigation and outpatient paediatric neurology opinion fell outside NICE recommendations of 2 weeks for first paediatric assessment.
- it was difficult for secondary services to systematically and easily identify children with epilepsy in their care.

The audit team made the following key clinical recommendations within the Children's Epilepsy Workstream in Trent:

Children:

1. With an epileptic seizure should have previous and current development and/or school progress documented at first assessment
2. With paroxysmal episodes should have the absence or presence of triggering or contextual factors documented
3. With convulsive episodes should have a standard 12-lead ECG with documented calculation of QTc. This recommendation chosen to align with SIGN guidelines as this was considered to be more easily implementable for all children with convulsive episodes (SIGN) as opposed to limited to those where there was diagnostic uncertainty (NICE).
4. With any paroxysmal event should have documented evidence of first aid advice
5. There should be evidence of involvement of a paediatric neurologist where appropriate.

All children with epilepsies:

1. Should have International League Against Epilepsy (ILAE) multiaxial diagnoses where possible.[10]
2. All children meeting the criteria for an MRI should receive MRI.
3. Children commenced on antiepileptic medication should have documentation of appropriate information; this should include discussion about pregnancy and contraception in females aged twelve and over.

Children without epilepsy:

1. Should not be treated with antiepileptic medication (unless for another specific recognised movement or pain disorder).
2. Should not have an EEG performed (unless for another specific disorder apart from epilepsy).

Key Service Recommendations:

1. All paediatricians involved in diagnosing, investigating and managing children with suspected epilepsies should have evidence of appropriate training (e.g. PET1 & PET2 or equivalent) and participation in relevant audit.
2. Children referred with paroxysmal episodes should be offered a first paediatric assessment within 2 weeks.
3. EEG and MRI services should be configured to allow assessment within a maximum of 4 weeks.
4. Paediatric services to support development of a ratio of one epilepsy nurse specialist to approximately 250 children with epilepsies.
5. Services should work towards systems that allow easy identification of patients for future audit and research purposes.

Conclusions and recommendations were used by the Children's Epilepsy Workstream in Trent to support an ongoing quality improvement strategy.

5. Discussion

The audit prompted a consideration of a number of issues regarding the practicality and effectiveness of a standardised multi-centre audit.

In arriving at the chosen methodology for this audit, alternative methods of reviewing quality of management had been considered. Independent clinical review of children's diagnosis and management, as has been reported in previous services evaluations,[11] was considered impractical when auditing services on a national scale. Clinical, rather than process, outcomes for children with epilepsies might provide an ideal measure of the quality of a service. However using clinical outcomes as an indicator for quality in a meaningful way seemed unrealistic at this time. The diagnosis of epilepsy covers a very heterogeneous 'case mix' and expected outcomes vary dramatically from one epilepsy to another. The ascertainment of the target population was difficult and time consuming.

The results obtained by this multi-cohort audit suggest differences in performance indicators between different centres

within a region. Statistical analysis of these results was not undertaken. The small numbers obtained, particularly for some performance indicators, raises difficulties when considering the significance of results and their variation. Results however were sufficient to provoke constructive discussion between different centres within a network and highlighted areas for development for different services. A network meeting with commissioners and providers was arranged and action plans developed for each service. To date ongoing audit and action plans for the region has resulted in demonstrably more epilepsy nurses, seizure clinics, young persons clinics and tertiary satellite clinics across the region. Clinical data capture tools, local care pathways and standardised letter templates have all been devised in response to audit findings (www.cewt.org.uk).

Although prospective audit for these children would have a number of benefits there are difficulties with this approach. Achieving complete ascertainment prospectively is challenging where children are managed in an array of different generic services. Also when prospectively auditing long term conditions a substantial lag time can occur between patients entering the audit and audit results. This audit demonstrated that a retrospective methodology can produce meaningful and timely measures of process that can inform service development.

The definition of "paediatrican with expertise" was subjective and varied from cohort to cohort. A more objective definition of paediatrician with expertise should be sought.

A second pilot using a 6 month capture period and EEG based ascertainment was planned following this audit pilot in order to determine the feasibility of a national audit, in terms of time commitment from local junior professionals undertaking the audit with a centrally-funded small project team. This further concluded that EEG ascertainment was achievable and that an average local cohort would require 15 h input (15 min data entry/child).

Although the segment of audit development outlined began over 7 years ago, the evidence base and resulting standards defining best practice have remained largely unchanged. The timeframe shows the importance of guideline implementation as a continuing process and how audit methodologies need to develop and improve in order to rigorously research quality and understand how outcomes relate to variation of intervention.

The BPNA and RCPCH commenced in 2009 the Epilepsy12 national audit.[11] This was a 3 year, Dept. of Health funded (~£500,000) national audit based on the Mid-Trent pilot and subsequent methodology revisions.

The Epilepsy12 audit used a similar methodology with the following adaptations informed by this Mid-Trent audit.

- Children were ascertained using first EEG neurophysiology databases. Those identified within a 12 month time window were further filtered to capture those who had a first paediatric assessment within the first 6 months.
- Using EEG ascertainment allowed community paediatric ascertainment.
- Providers were grouped together into pragmatic audit units and regional tertiary units.
- 'Paediatrician with expertise' was defined according to the Edinburgh Consensus Conference.[12]
- A census day was created such that all participating audit units aligned to describe how their services were resourced at the same point in time.
- A patient related experience measurement tool was created.
- Data accuracy was improved by using a webtool with validation, a data cleaning phase and kappa testing for inter-observer variability.
- Epilepsy12 round 1 was successfully completed and published results September 2012.[11] 186 audit units submitted data on a total of approximately 5000 children.

6. Conclusions

Effective audit is an essential component to aid implementation of national clinical guidelines and improvement in the quality of health care. There are advantages in undertaking large scale systematic audit as they allow variation to be captured; resource peer-to-peer learning and inform policy at local, regional and national tiers. There is no reason why the methodologies used in audit should not be as robust as those used in effective clinical research. This audit illustrates the successful evolution of a small single centre audit to a large scale multi-centre audit for an important and complex long term group of conditions.

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